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ABSTRACT

As the inpatient population in New York State psychiatric centers declines, many mentally disabled persons are returned to their families. This study examined the needs of those individuals and their families after the client's discharge. Interviews were conducted with 116 individuals who had received services from a New York State adult psychiatric center, a significant other identified by each of these mentally disabled adults, and parents or family members of 38 children who received psychiatric services from a New York State Children's Psychiatric Center. The findings suggest that families of discharged mentally disabled individuals are placed under a great deal of stress when that individual returns home. Many of the families reported experiencing tension as a result of living with a mentally disabled relative. Several families noted that family life and social activities were restricted by the presence of the client. Aftercare services, received by 80% of the clients, did not appear to reduce the families' needs. Data analysis revealed that certain factors were indicative of which families were most at-risk of having several service problems when the client returned home; these factors included client's behavior and chronicity, marital client returned home: client's behavior and chronicity, marital status, and the presence of a second relative with mental illness. (Included in the report are summaries of major findings and recommendations, 13 tables, and 5 figures.) (NB)

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FAMILIES OF THE MENTALLY DISABLED: STRESSES AND NEEDS WHEN A RELATIVE RETURNS HOME

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TABLE OF CONTENTS

		page
SUMMARY OF MAJOR FINDINGS		i
SUMMARY OF RECOMMENDATIONS		iii
I.	INTRODUCTION	1
II.	METHODOLOGY	4
III.	DESCRIPTION OF SAMPLE	9
	A. Client	9
	1. Demographic and social characteristics	9
	2. Psychiatric characteristics	10
	3. Functioning and behavioral characteristics	11
	B. Family Member	13
IV.	MAJOR FINDINGS	14
	A. Families Under Stress	14
	B. Problems in Nine Major Service Categories	16
	C. Identification of Families At-Risk	21
V.	FINDINGS ON A SUBSAMPLE OF MENTALLY DISABLED CHILDREN	25
VI.	SUMMARY AND IMPLICATIONS	28
VII.	RECOMMENDATIONS	32

MAJOR FINDINGS

1. Of the 116 former clients in the study, most were white and unemployed, half were males, and about half were under the age of 40.

2. The majority of clients had been diagnosed as Schizophrenic and 50 percent met CSS eligibility criteria for chronicity. According to rating scales employed in the study, more than half of the clients were experiencing little psychiatric impairment, although a significant number were functioning at a low level and were displaying behavior problems.

3. A large proportion of the sample was receiving some follow-up care with 82 percent receiving aftercare and 58 percent receiving services from a social worker. In addition, 80 percent of the clients were receiving some form of medication. About a third of those medicated appeared to be at a high dosage level and in a few cases there were indications of polydrug violations.

4. In response to open ended questions about their overall problems and needs, families reported a need for family counseling, increased daytime activities for the clients, and financial assistance.

5. According to family members interviewed, the presence of the returned client created a high level of stress for the family. Approximately one-half of the families reported that they felt burdened. The families were frequently forced to make drastic life-style changes such as restricting their leisure activities.

6. When asked to identify problems in nine specific areas, (Social-Emotional, Employment, Transportation, Homemaking, Food and Clothing, Housing, Legal, Education, Health) two-thirds of the interviewed families reported a major problem in at least one area and 40 percent stated that they had two or more problems.

7. The families' subjective report of stress was highly related to their identification of problems with the clients.

8. Of the nine areas, the Social-Emotional area was the most frequently cited. Transportation and Homemaking problems were the next most frequently mentioned.

9. There were subgroups of families who were more likely to have service needs in areas beyond the Social-Emotional area. Those families with older clients, clients who were parents in the family, and poor families were found to be the most likely to experience multiple problems at high levels.

10. The number of problems that families mentioned was related not only to client factors, but also to family factors. While the client's functioning, behavior and psychiatric history were important, marital status and the presence of a second family member who was mentally disabled were also highly related to problems.

11. A small subgroup of families with children who were psychiatrically impaired were included i the study. These children were often hospitalized for long periods of time and were as likely as adults to have problems. However, they were much less likely to receive aftercare services.

SUMMARY OF RECOMMENDATIONS

The findings of this study indicate that the Office of Mental Health must give greater attention to the needs of the families of mentally disabled individuals. Clearly, this can be accomplished only with the active support and participation of other state agencies. In order to support efforts to establish policies and programs that will help families caring for mentally disabled individuals at home, the following recommendations are offered:

1. Services to be provided to mentally disabled individuals discharged to families should be specified in writing and agreed upon prior to the release of clients in a joint consultation between the psychiatric center staff, the family members and the client.

2. It is recommended that family members be actively involved in discharge planning when their participation is appropriate and desired by the client.

3. It is recommended that the Office of Mental Health establish as a priority the training of professional staff who work with mentally disabled clients residing in family settings.

4. It is recommended that a wide variety of family education programs be developed for family members who are living with mentally disabled relatives.

5. The Office of Mental Health's Committee on Therapeutics should thoroughly review medication policies and develop a policy or structure to monitor the medications of clients who live at home.

6. Caseworkers and other direct service providers should be encouraged to maximize the use of informal supports in meeting the needs of mentally disabled individuals and their families.

7. The Office of Mental Health should expand guidelines for local assistance programs to allow for the funding of informal support services for mentally disabled individuals and their families.

8. The Office of Mental Health should explore the most feasible and effective means of providing aftercare and supportive services for children and their families.

9. Unless greater attention is given to the needs of families along the lines suggested above, it is recommended that the Office of Mental Health reconsider policy initiatives which assume that family members are appropriate substitutes for professional and para-professional mental health workers.

I. INTRODUCTION

> The policy of returning mental patients to their own communities assumes that the family will support individuals who can barely take care of their personal needs...Furthermore, little effort has been made to cite the responsibilities delegated to the family in the context of community care. (Segal, 1979, p. 521)

In the fifteen years since 1965, the inpatient population in New York State psychiatric centers has dropped by over 70 percent. This drastic reduction in psychiatric hospital populations, from 85,000 to 24,000, and the concomitant increase in the number of mentally disabled individuals living in communities across New York State, has caught the attention of the media, researchers, policymakers, and the public.

Among the deinstitutionalized, those receiving the most attention are clients released to the community to live on their own. Various articles and studies have focused on this significant group of discharged patients. Almost totally lacking, however, is any attention to the large number of former patients who are returned to their families. Since these clients are living with relatives, they are less conspicuous and, therefore, little community concern or policy direction is aimed at the needs of this important group. Yet, according to statistics maintained by the Office of Mental Health, approximately 40 percent of all discharged mental patients are returned to their families. Despite the magnitude of this phenomenon, little is known about the consequences of deinstitutionalization on the families of the mentally disabled. It is important, therefore, to examine

the needs of the families as well as the role of the family in providing services to the discharged client.

In spite of the apparently obvious need to study the effect of deinstitutionalization on the families of the mentally ill, this issue has received scant attention in the literature. A review of relevant studies reveals that only a few have focused on the consequences of the client's homecoming from the perspective of family members. One early study found that families with a relative who is mentally impaired are more tolerant of this person's deviance than community members (Dinitz, Angrist, Lefton and Pasamanick, 1961). Another study, by Freeman and Simmons, found that families most easily accept a client who is in an important position in the family, i.e., a person in a central role, necessary to other members of the family (Freeman and Simmons, 1958). One of the most recent and most important studies found that the salient factor in determining the family's ability to accept the client after psychiatric hospitalization is the amount of symptomotology exhibited by the client (Doll, 1976). According to Doll, the former patient's display of bizzare behaviors was more important to the client's successful reintegration to the family than other factors. In addition, he found that in some families, physical acceptance of the client was accompanied by social and emotional rejection of the client. Families seemed willing to take the former patient back into the home but a great deal of emotional tension was perceived in the subsequent family interactions. In light of this recent finding, examination of the family's reaction to a returning mentally disabled relative is imperative.

While it is important to assess the needs of families with mentally disabled relatives in order to address this conceptual lacuna in the

literature, it is vastly more important to study the needs of these families for the purpose of enhancing services to families and clients. With this in mind, the New York State Council on Children and Families, in conjunction with the Office of Mental Health and the Governor's Interagency Task Force on Mental Health Community Support Systems conducted a study of families with mentally disabled members. The agencies that were members of the sub-task group responsible for major decisions regarding the design of the study were: the Department of Social Services, the Offices of Mental Health, Aging, and Mental Retardation and Developmental Disabilities, the Division of Budget and the Council on Children and Families. The Disabled Children's Program was also included in this sub-task group. This study represents a concerted effort by the agencies involved to address the policy and program vacuum that surrounds families with a mentally disabled relative. It is an attempt by New York State policymakers to increase their ability to make informed policy decisions, which will help eliminate the service void that currently exists for families with mentally disabled members.

It is clear from the results of this study that families are placed under a great deal of stress when a mentally disabled relative comes home. As the following report indicates, many of the families in this study experienced tension as a result of living with a mentally disabled relative. Several families noted that family life and social activities were restricted by the presence of the client. In spite of the fact that 80 percent of the clients were receiving aftercare services, this resource did not seem to reduce the families' needs. This may be because these services generally focus on individual clients rather than addressing the

needs of the client in conjunction with his/her family. Families seem to be indicating that aftercare services must be more broadly defined and include the concerns of those who care for and house a mentally disabled relative. To help families cope with the burden of caring for a discharged client, families most frequently requested support services in the Social-Emotional area, such as family and marital counseling and individual therapy for the client. In addition, needs were apparent in other service areas such as Transportation and Homemaking. Families who requested help in Transportation said that they had difficulty in getting the client to activities. Homemaking problems, which developed when families tried to meet clients' custodial needs, were also described by some families. It is clear from the analysis that certain factors were indicative of the families most at-risk of having several service problems when the client came home. These factors included the client's behavior and chronicity, and certain family characteristics, such as marital status and the presence of a second relative with mental illness. This report summarizes the findings from the study and details the major implications derived from the data. These implications should be considered by policy-makers if the state is to succeed in its efforts to relieve the stress and needs of families who are coping with the return of a mentally disabled relative.

II. METHODOLOGY

For this study, a sample of 116 individuals who had received services from a New York State adult psychiatric center was interviewed.[1] A significant other, i.e., a family member identified as an appropriate

[1] In addition, staff at Dutchess County Community Mental Health Center volunteered to collect data on a sample of their clients. However, because these clients were from a county community mental health center, and not a psychiatric center, these 10 cases were excluded from the analysis.

informant by the client, of each of these mentally disabled adults was also interviewed. In addition, parents or family members of 38 children who received psychiatric services from a New York State Children's Psychiatric Center were interviewed.

The principal sources of information for this report were an interview with the relative and an interview with the client. Additional information on current and former inpatients' psychiatric histories was obtained from the Office of Mental Health.

An interview instrument was designed with the help of the members of the sub-task force group. The purpose of the instrument was to collect information from family members and clients in the following areas:

- Demographic and Social Characteristics of the Sample.

  This included information such as age, race, sex, income and marital status.

- Assessment of the Clients' Activities.

  These data were obtained from clients, who were asked to describe in an open-ended question how they spent the weekday immediately preceding the interview.

- Indicators of the Clients' Psychiatric Impairment.

  Interviewers used the Global Pathology Index of the Brief Hopkins Psychiatric Rating Scale (Derogatis, 1974) to rate the clients' level of illness. This Index, using a nine point scale ranging from absent to extremely mentally ill, provided interviewers with an objective means of evaluating the clients' mental illness. In addition, family members were asked to rate the client's level of mental illness during the week preceding the interview on a five point scale (ranging from "extremely" to "not at all" mentally ill).

- Clients' Level of Functioning.

  This data was culled from a series of 14 specific questions asked of family members about the former patients' level of functioning. Some of the questions asked were: does the client use public transportation on familiar and unfamiliar routes; drive a car; or engage in leisure time activities. Answers to the 14 functioning items were added together to construct a measure of the client's level of functioning. All of the 28 items used to evaluate the clients' functioning and behavior were acquired from the Office of Mental Health, which has used these questions on several client reporting instruments.

- Clients' Behavior Problems.

  This information was obtained in a manner similar to the data on clients' functioning. The family member was asked another series of 14 questions such as: has the client had trouble at work or school; caused community complaints; or destroyed property. Answers to these 14 items were added together to construct an overall measure of behavior problems.

- The Families' Subjective Reaction to the Clients' Return.

  In several open-ended and fixed response questions, families were asked if living with a mentally disabled relative was a burden and to describe the major changes in family life that had occurred since the clients' return.

- Clients' Receipt of Aftercare Services.

  Several questions were asked about the aftercare services that the clients received, including their medications. The types of drugs used and the doses prescribed were coded by a consultant familiar with psychotropic medications. Drug doses were categorized as light, moderate or heavy on the basis of doses recommended in the Physicians Desk Reference.

- Service Problems and Needs.

  The families were asked about specific service problems and needs in the following nine areas:

  1. Social-Emotional (e.g., family tension or the client's loneliness);
  2. Transportation (e.g., getting the client/family members to scheduled activities);
  3. Homemaking (e.g., custodial care for the client);
  4. Employment (e.g., lack of job opportunities for the family and client);
  5. Food and Clothing (e.g., not having enough food and/or clothing);
  6. Housing (e.g., lack of privacy or space);
  7. Health (e.g., lack of adequate information on psychotropic drugs);
  8. Education (e.g., lack of sufficient education required by employers); and
  9. Legal (e.g., child custody problems).

The information detailed above was collected during an hour interview conducted by facility staff from participating centers. Facilities were selected on the basis of the size of their inpatient population and their geographic location. The nine psychiatric centers that agreed to cooperate were:

- Rochester Psychiatric Center
- Gowanda Psychiatric Center
- Kings Park Psychiatric Center
- Utica/Marcy Psychiatric Center
- Hudson River Psychiatric Center
- Elmira Psychiatric Center
- Rockland Psychiatric Center
- Bronx Psychiatric Center
- South Beach Psychiatric Center

Each facility director was asked to contribute the time of two psychiatric social workers to the study for a two week period. In some instances, psychiatric social workers were not available and facility directors assigned mental hygiene therapy aides, nurses, psychologists or facility research staff instead. All facility staff who participated in the study were trained in the use of the instrument during a one or one-and-a-half day training session and then conducted the interviews.

Information on the frequency and duration of the clients' psychiatric admissions, used to measure the client's chronicity, was obtained from the Office of Mental Health. Chronicity was defined on the basis of eligibility for community support services; those who were eligible were considered chronic. To be eligible, clients must have had either extended or frequent psychiatric hospitalizations.

In general, subjects included in the sample were drawn from a pool of clients whose names were randomly selected from hospital records. Program evaluation or research staff at the psychiatric centers were asked to select clients based on a randomization procedure.

A major portion of the sample consisted of previously hospitalized individuals who were living with family at the time of the interview. For comparison, a smaller number of never hospitalized outpatients, inpatients awaiting discharge, and former clients living with non-family in the community were also included. Psychiatric center staff were asked to select only clients whose record included the name of a significant other. These lists of names, and telephone numbers when available, were then given to the interviewers. Interviewers were instructed to contact the client by telephone and request permission to interview the client and a family member. Many of those on the list could not be contacted; some telephone numbers were unavailable from the hospital, unlisted, or disconnected. Often, there was no answer at the household after several tries. Once contacted, many families refused to be interviewed. It was especially difficult to include participants from New York City and Long Island. One diligent downstate interviewer went through over 70 names before finding 10 families willing to participate.

Clients who agreed to participate were asked to sign a consent form indicating their understanding that their own participation was totally voluntary and that a family member would also be contacted and interviewed. Significant others were also asked to sign a consent form. This sampling procedure may have screened out lower functioning clients (those unable to make and keep an appointment), higher functioning clients (those unwilling to be involved with the psychiatric center), poorer clients (those without a telephone), and more severely disturbed clients (those too threatened by the request for an interview to participate). As a result of this sampling procedure, in particular the reliance on voluntary participation, it is difficult to estimate the representativeness of this

sample compared to the general population of Office of Mental Health outpatients. However, in an attempt to evaluate the representativeness of the sample, the data from this study will be compared with another sample of Office of Mental Health outpatients. This comparison will be included in the Description of the Sample.

In addition, 38 families with young, mentally disabled children were interviewed. This subject group was drawn in a manner similar to that used to select the adult sample, from the records and staff of five psychiatric centers; Rochester Psychiatric Center, Utica-Marcy Psychiatric Center, Hudson River Psychiatric Center, Rockland Children's Psychiatric Center and Bronx Children's Psychiatric Center. The child's mother was the typical respondent. A brief, but separate analysis of the results of the interviews with the parents of young children is presented later in the text.

III. DESCRIPTION OF THE SAMPLE

In order to obtain a better understanding of the needs of patients and their families upon patients' return to the community, basic information about the clients and their families was obtained. This information will be presented in several subsections which will describe the clients' demographic and social characteristics, their psychiatric, functioning and behavioral characteristics and the demographic and social characteristics of the family member interviewed.

A. Client

1. Demographic and social characteristics

The clients' demographic and social characteristics are presented in Table 1. Clients' were evenly distributed in terms of sex and nearly

90 percent were white. They had a mean age of 40 years and the largest

Table 1 About Here

number of clients were in the age category between 26 and 40 years. About one-quarter of the clients were married and close to 80 percent were unemployed.

2. Psychiatric characteristics

Table 2 displays information on the clients' psychiatric history and status. At the time of the interview, 71 percent of the sample were discharged patients. Many of the clients included in this study were first

Table 2 About Here

admitted as young adults, sometime between their 21st and 35th birthday. The majority of the clients had been diagnosed as Schizophrenic (62%). Most of these clients were taking medications prescribed for their mental illness (80%). In fact, 48 percent of those taking drugs were taking a major tranquilizer and about 40 percent were taking more than one medication.[2] Similarly, all but 18 percent of the clients received some form of aftercare services such as visits to the outpatient clinic. Many of the former patients interviewed for the study of family support systems were not judged by interviewers to be severely mentally ill. According to interviewers' judgements, based on the Global Pathology Index, over half of the clients were rated as being either "not mentally ill at all" or had less than a "moderate" degree of impairment on the day of the interview. Approximately 60 percent of the sample had been hospitalized for one year or less and close to 40 percent had been hospitalized for no more than six months.

[2] In a few cases (11) clients had been prescribed two of the same type of psychotropic drugs at the same time. This appears to be a violation of the polypharmacy guidelines. (Psychotherapeutic Drug Manual, published by New York State Department of Mental Hygiene, November, 1977.)

3. Functioning and behavioral characteristics

Families were asked several questions about their perceptions of the clients and the results of these questions appear in Table 3. Some interesting responses were reported when family members were asked if clients could perform a series of 14 tasks independently, with assistance,

Table 3 About Here

or not at all. While over two-thirds of the clients were able to use public transportation on familiar routes independently, close to a third were completely unable to use public transportation on unfamiliar routes. Fifty-five percent of the clients were unable to drive a car and about 40 percent were not able to engage independently in leisure time activities or socialize with others.

Family members were also asked about the client's behavior problems. As can be seen in Table 4, almost a third of the clients had serious trouble at work or school and over one-quarter had a serious problem with

Table 4 About Here

inactivity; that is, they did nothing most days. Less than 5 percent had a serious problem with causing complaints from people in the community, destroying or stealing property, or disturbing others with unacceptable sexual behavior.

Individual client's scores on the functioning items were summed in order to develop a general measure of functioning. For analytical purposes, one-third of the clients, who could perform most tasks independently, were grouped into a high functioning category. Those clients in need of assistance in several areas, also about a third, were labeled moderate functioning. The remainder, those clients who often needed help in their daily activities, constituted the low functioning group. The behavior items

were summed in a similar fashion, but only two categories of behavior problems emerged. Those who had many behavior problems were placed in one group and clients who rarely had a problem became the other group. The results of these general measures of functioning and behavior appear in Table 5. Two-thirds of the clients were high or moderate functioning

Table 5 About Here

and 38 percent had little or no behavior problems.

An assessment of the activity level of the client was obtained from the client's own report of his/her daily activities. At the beginning of the interview with clients, social workers asked them to describe, in their own words, what they did on the previous weekday. These results appear in Table 5. Thirty-two percent had no interaction outside of the house that day and around 70 percent of these former patients interacted only with immediate family inside the house. Thirty-nine percent were rated as being very inactive. These inactive clients did nothing but watch television, listen to the radio, eat and sleep for most of the day. Another 35 percent were involved in only moderate activity, such as going to the store or occasionally performing chores around the house.

In order to assess the similarity of the demographic and psychiatric characteristics of these subjects to a larger population, the clients included in this sample were compared with another sample of Office of Mental Health outpatients. This larger sample of Office of Mental Health outpatients were subjects in a Community Support System study of 624 clients. The Office of Mental Health study reviewed outpatients use of aftercare services at five sites -- three demonstration sites with model Community Support Systems already in place, and two comparison sites where traditional outpatient treatment services were in operation (Lannon, 1980).

As can be seen in Table 6, the two samples are very similar on sex, race,

Table 6 About Here

age at first admission, diagnosis and receipt of aftercare services. However, the two samples are dissimilar in that the clients reported on here are younger, more likely to be married, have shorter lengths of stay, and appear to be less mentally ill. Thus, despite the striking similarity of these two samples on demographic characteristics, they are markedly different on certain important psychiatric characteristics, particularly the length and severity of their mental illness.

B. Family Member

The sex, race, age, relationship to the client, employment status and income of the family member interviewed appear in Table 7. Most of the respondents were white and female (89% white, 68% female), and the mean age was 51 years. Close to half of those interviewed were the parents of

Table 7 About Here

a mentally disabled person. The next largest relationship category was spouse (28%). Nearly 60 percent of the respondents were unemployed and about half of the families were poor, i.e., had an income of $10,000 a year or less. Ten percent had a somewhat high annual income of over $25,000, yet 70 percent of the 116 families received some income that was not earned, most often Supplemental Security Income (27%) or Social Security Benefits (47%). In addition to being poor, some of the families had other problems, too. Over 30 percent had a family member, in addition to the identified client, who had received treatment for mental health problems and 36 percent of the families included a person with a physical disability or health problem. When family members were asked about their perceptions

of the clients' degree of psychiatric impairment, these relatives rated almost 70 percent of the clients as not at all or only mildly mentally ill.

IV. MAJOR FINDINGS

Although it was noted in the preceding section that many clients are receiving aftercare services, it is very clear from interviews with families that many problems still exist. Some of these problems involve the family's emotional difficulties in living and interacting with a mentally disabled relative. Other problems are more specific in nature and relate to the availability and delivery of services in nine major service categories. The following sections of the report will present the major findings related to the stress of having a mentally disabled relative living at home and the service needs of clients and families.

A. Families Under Stress

One of the most important findings that this study has generated is an increased awareness of the extent to which families are under stress as a result of residing with a mentally disabled family member. For a large portion of the sample, there were problems interacting with and supervising the clients, and life-style was restricted by the presence of the client.

Families were asked several questions about their subjective reactions to the client's return. A frequent and critical point made by families was that they felt emotionally drained by the return or presence of the former patient. Three questions reflect the significant other's reaction to the emotional demands of living with a mentally disabled relative. The responses to these questions are displayed in Table 8. In the first of these, the respondent was asked if having a mentally disabled person living with the

family was a burden. Nearly 50 percent said yes. When asked to elaborate

Table 8 About Here

on why there was this burden, respondents most often mentioned the client's need for supervision and care. Family members said that they felt they were unable or lacked sufficient ability to take care of the client's daily needs and monitor the client's behavior. A second indicator of the client's effect on family life was obtained from a question which asked whether the reintegration of a mentally disabled relative created a major change in the family. Forty-seven percent of the families felt there had been a significant alteration in family life. Many of these relatives described the change as the creation of tension within the family unit, and the case below illustrates one way in which a client living with the family can create tension among family members:

> An elderly Bronx widower reported that his 29 year old mentally disabled son sometimes created tension between himself and his other adult children. His daughter was concerned about her father's health and wanted him to move in with her. However, the daughter was not able to provide for both her father and her brother. As a result, this 72 year old gentleman, barely able to provide for himself, reported that he was unable to move in with his daughter and he was burdened by having to supervise and monitor his son's activities.

In a third effort to understand the increased stress for the family living with a discharged client, respondents were asked if living with the former patient affected their use of leisure time. As can be seen in Table 8, about half said yes. Family members noted that because the client could not be left alone, they were limited in their freedom to pursue recreational interests. Relatives also said that the time they had to socialize with friends was restricted by the presence of the client. Thus, as a result of the stress of living with a mentally disabled relative, families had a

variety of needs. The specific service problems that family members described are detailed below.

B. Problems in Nine Major Service Categories

During each interview, the family member was asked many questions about the specific service problems and needs that his/her family had experienced since the client came home. (If the client was awaiting discharge, the family member was asked to project what he/she felt the problems and needs would be if the client came to live with them.) Family members were asked in-depth about nine specific areas of concern: Social-Emotional, Employment, Transportation, Homemaking, Food and Clothing, Housing, Legal, Education and Health. Clients were asked about the problems they had in each of these areas as well.

The percentages of family members and clients who said that there were problems in each of these areas are presented in Table 9. As

Table 9 About Here

can be seen, both clients and family members identified relatively few problems. Both groups, rather than identifying needs in many of the areas mentioned, were quite selective. Overall, the clients had a tendency to identify more problems than the family members. In spite of this slight difference in the perception of the number of problems, there is general agreement about which problems are the most important. Both clients and their family members reported Social-Emotional problems most frequently (38% and 45% respectively). This was the most important problem for both groups and the types of needs that were frequently expressed in conjunction with Social-Emotional problems included requests for outpatient psychiatric services and personal or family counseling. The opportunity for increased social interaction was also a frequent concern. The Social-Emotional

problems of one poverty-stricken, upstate, urban client provide a good example of how devastating the impact of mental illness on the family can be.

> "I carry this terrible feeling of loneliness with me all the time. I can't communicate with people. I don't find people I can trust and open myself with. Things are not so important, I can live without them, but I need a friend my age - a real close friend. My daughter is my closest friend and my big help, but she is only 18. There are many things I can't talk about with her."
>
> "The activities at the psychiatric center are depressing because everyone goes there because they are lonely and have nothing else to do. In the end, it's too depressing for me. The doctors are always around reminding you of your problems and your sickness. My daughter is my only friend. She is my constant companion and she is very understanding. I talk to her a lot."

As can be seen in Figure 1, families and clients reported other types of concerns beyond Social-Emotional problems. The other problems frequently

Figure 1 About Here

mentioned by families were Transportation (21%), Homemaking (20%), Housing (19%), and Employment (19%). Clients reported problems in most of these areas, although not in the same order. Many more clients mentioned Employment problems (36%). Other problems that clients said they had were Transporation (27%), Food and Clothing (20%), and Housing (15%).

In the area of Transportation, families asked for increased special transportation, such as buses that would run from the client's home to the psychiatric center, or other community programs, and reduced rates on public transportation. Because so few of the clients could drive, families had to provide transportation to jobs and/or social activities. Family members felt this was a hardship and it restricted their own

schedule. For example, one family member said, "Transportation is a problem since I don't drive and no one else wants to bother to take her (the client) places."

Families reported Homemaking problems in keeping up with the clients' needs for custodial care. Consequently, there were requests for respite housekeeping, chore services, and day care, which would free the family members from the client's care requirements during the day and enable them to accomplish necessary household tasks. One woman noted, "I need a vacation and need relief from caretaking." In addition to these housekeeping problems, nearly one-fifth of the families also had problems adequately housing themselves and the client. The Housing problems that were cited seemed to relate to economic problems. For example, requests were made for subsidized housing as well as assistance in home repairs. In addition, a few families requested that alternative housing for the client be available, other than residence with the family.

Clients and families identified Employment problems and said that job training and job counseling would help them to deal with these problems. Also, some clients and their families requested more sheltered and supported employment opportunities for former patients returning to their families.

In addition to the family and client perceptions of service needs, a more objective assessment of needs was desirable. Therefore, after the interviews were completed, the psychiatric center staff who conducted the interviews were asked, via telephone, to rank the three most important areas of concern for the families they interviewed for the study. The answers to this question are presented in Table 9. As can be seen, psychiatric center staff ranked Social-Emotional problems first, Employment problems second and Transportation problems third. Thus, there seems to be a high

level of consensus among clients, family members and psychiatric center staff that these three issues (Social-Emotional, Employment. and Transportation) present the greatest problems for mentally disabled persons who return home.

In summary, then, problems in the Social-Emotional area such as isolation and increased tension in the household were expressed by family members almost twice as often as any other problem area. Clients and interviewers perceived problems in this area to be most important. These data indicate that programmatic efforts in the Social-Emotional area should be a service priority for all families caring for mentally disabled relatives.

Further analysis revealed that there were certain subgroups of families for whom other areas of need are crucial. In particular, those families in which the client is a parent or an elderly person need more than just Social-Emotional services. As might be expected, clients returning to families in which the annual income is less than $10,000 also have problems in many areas. As can be seen in Table 10, the families of elderly clients,

Table 10 About Here

clients who are parents, and poor families mentioned many more problems than families in the total sample reported.

These data show that when the client is the parent of the family member interviewed, there is a greater likelihood of problems. These relatives (who are the adult children of the client) may not have the resources to care for their mentally disabled mother or father. Because clients who are parents are in the older age categories, it is not surprising that they have several of the same problems that elderly clients have.

The data on the problems of families with aged clients (61 to 86 years) are compared to the problems reported by the total sample in Table 10. The groups of problems reported by families that have an elderly client (Social-

Emotional, Housing, Employment, Homemaking, and Health) suggests that these clients may require extensive, often custodial care from the family. Many of the 44 percent who noted Homemaking problems said that providing for the client's daily needs was difficult. For example, cooking and cleaning for the client created problems for the family member. The client's need for the provision of custodial care may also cause employment problems for the caretaker. Fifty-six percent of the significant others caring for these elderly clients reported employment problems. Some of the problems reported by families caring for aged clients may be typical in any family living with and providing for an elderly relative.

Improverished families also reported more problems than other families in the sample and this may reflect the impact of their economic deprivation. Families who are very poor (under $10,000) have more problems with Food and Clothing, Transportation and Employment. Support services in these areas are clearly needed most by those at low income levels. Although not included in Table 10, there is another income group that also reports several problems. This group is in the middle income range. Even though the report of Housing, Homemaking and Employment problems is rare in lower-middle income levels (from $5,000 to $15,000), there is a sharp increase in the report of these three problems at the $20,000 to $25,000 range. Many of these higher income families stated that they had Housing, Homemaking and Employment problems. These families may have higher incomes because they have two wage earners. The demands of employment, in addition to the care requirements of a mentally disabled relative, could be related to the report of problems in these areas.

While the number of families in each of these subgroups of clients is small, they reported problems at much higher levels than other groups in

the study. These families are struggling with complex and difficult situations and they are in need of the attention of service providers. The next section will systematically examine client and family characteristics that define other families with problems, those that are at a high risk of reporting problems in two or more of the major problem areas.

C. Identification of Families At-Risk

Additional analysis was required to further specify families most at-risk of being severely strained by the client's return and, therefore, it was necessary to determine what factors are related to the number of problems that families report. Identification of families at-risk will increase the ability of policymakers to target services to the most needy families. In order to accomplish this, the number of problems that families mentioned in the nine major service areas were added together and families were separated into three categories. It was found that a third of the families were without problems, 27 percent of the families had one problem and 40 percent had two or more problems. These three groups of families were then compared on all important variables.

Not unexpectedly, the incidence of problems was highly related to families' perception of stress. As shown in Figure 2, the families who

Figure 2 About Here

said that the client was a burden, that major changes were required by the client's return, or that the client inhibited the amount of and use of family members leisure time reported more problems. The relationship between the number of problems reported and each of these three variables was found to be statistically significant. It seems then that the

emotional adjustment of the family is highly related to the family's perception of problems and the number of problems that families express.

Of all the other variables derived from the questionnaire, two groups emerged as being related to the number of problems reported by families. These variables clustered in two dimensions, client and family characteristics.

Several client characteristics which were found to be significantly related, in the statistical sense, to the number of problems that family members noted were: the client's chronicity, behavior, and functioning ability. Interestingly, these three client characteristics were more important than the client's level of mental illness as rated either by the interviewer on the Global Pathology Index or the client's family member. As can be seen in Figure 3, the most important of these three variables

Figure 3 About Here

was the chronicity of the client. Seventy-five percent of the chronic clients are living in families with one and two problems. In fact, twice as many of the problem families have clients who are chronically ill.

The graph in Figure 4 makes it clear that the client who has created

Figure 4 About Here

concern with inappropriate behaviors is also likely to be perceived as problematic. Almost half (47%) of these clients who act out had a family member who expressed several problems in the nine areas.

The client's functioning level is also compared with the level of problems that families have in Figure 4. Very few (17%) of the clients who were high functioning and performed daily activities independently had relatives who stated there were two or more problems, yet a significant proportion of the moderate and low functioning clients were in families

that reported multiple problems (58% and 43% respectively). Thus, it seems that those clients who required day to day help in functioning activities or who need supervision to control their behavior may exhaust the families' resources.

The second group of variables, family characteristics, were also related to the number of problems families mentioned. The client's marital status and the presence of a second family member with mental health problems were associated with the incidence of problems. Both of these statistically significant relationships are displayed in Figure 5. According to the data, a divorced client was quite likely to

Figure 5 About Here

be in a family that reported two or more problems -- almost 75 percent of the divorced subjects were distributed in this way. Those clients who never married are likely to be in families that stated that they have at least one problem, but the majority (57%) of the married clients have spouses who reported no problems. Marital status then is a factor which reflects the families' ability to reaccept a mentally disabled member.

The family who has had a second family member with mental illness is clearly at-risk of experiencing problems when the disabled client returns home. Only 16 percent of these families had no problems, while the majority (56%) noted that they had several concerns.

Given that both of these factors proved to be important in identifying those families with problems, further analysis was conducted to examine the relationship between these variables. Of particular interest was whether the association between one set of factors and the existence of problems could be explained by the relationship of other variables. For example, marital status was related to chronicity and both marital status and

chronicity were related to the report of problems. Therefore, it was possible that marital status was only important because certain subgroups of clients, such as the divorced, were more likely to be chronically ill. A multi-variate analysis revealed that both family and client variables were important in explaining problems. The client who is chronic or has behavior problems causes problems for the family, regardless of marital status. Similarly, the families of divorced/widowed/separated clients have multiple problems, regardless of the client's behavior or chronicity.

Interestingly, even though 66 percent of the widowed/divorced/separated were reported to be without behavior problems, they were still perceived as more problematic than the never married or married clients. This analysis demonstrates that both of these dimensions are necessary to explain why some families are more at-risk than others. It is not just client characteristics, such as behavior or chronicity, or just family characteristics, such as marital status, but both of these factors which are needed to identify multi-problem families. On the basis of these results it can be concluded that a family is most likely to be at high risk of reporting problems if they are caring for a chronic client, a client with behavior problems, a divorced client or a client who is not the only mentally ill member of the family.

It appears from this discussion that the client who is in a high risk family places extensive demands on the family for care. These dependent clients drain the family's resources and may often cause conflict between family members. One daughter caring for her chronically mentally ill mother graphically described the intra-family tensions created by her mother's return.

> "She's a pain in the ass for one thing. She made me nervous. My husband started drinking and almost left me. Plus she was so hard on the kids that one of them ran away from home."

In order to prevent such an outcome, discharge planning in these high risk cases must strive to achieve a balance between the needs of the client and the client's family. Even when return to the family seems to be the best alternative for the client, the impact of his or her return upon the family must be considered. When clients are returned to their families, support services such as self-help groups, respite and family counseling should be available. In the event that placement with the family is not feasible, client and family interactions should be encouraged by obtaining residential placements close to the family's home.

V. FINDINGS ON A SUBSAMPLE OF MENTALLY DISABLED CHILDREN

While not part of the major study of adult mentally disabled clients, it was determined that families with young mentally ill children should be the focus of special study, so that an understanding of their particular needs could be gained. As mentioned earlier, the families of 38 children were interviewed. Most of the children included in the sample had been previously institutionalized and were currently living with their families, but seven (19%) were awaiting discharge at the time of the interview. The demographic characteristics of these children and the family member are presented in Table 11. Most of the children were over ten years old, and

Table 11 About Here

the median age was 14. Sixty-one percent were Caucasian, 39 percent were Black or Hispanic, and most were males (71%).

The child's parents were generally fairly young, with 58 percent being no older than 40. Fifty percent of the families lived in urban areas, and close to a third lived in rural communities. Half of the families were

poor (with an annual income of $10,000 or less) and the same percent received some unearned income (about a third of the families used food stamps, for example). Yet only 21 percent of the families reported that they needed financial assistance. Like the families with an adult mentally disabled member, close to a quarter of the families with a disabled child reported that there was another family member who had received treatment for mental health problems.

The children included in this sample seem to represent a fairly disturbed population. As can be seen in Table 12, 11 of the 38 (42%) were diagnosed as schizophrenic or psychotic. While only 38 percent

Table 12 About Here

were taking a medication, the length of most recent stay for 55 percent of the children was between six months and three years.

In spite of these extended lengths of stay only 47 percent of the children were reported to be receiving aftercare while 82 percent of the adults were receiving aftercare. Another interesting finding is that 70 percent of the children meet the hospitalization eligibility criteria for Community Support Systems services, but are excluded from receiving Community Support services according to policy regulations because they are under 21.

When asked whether or not their child was a burden, 47 percent responded in the affirmative. Like relatives of adult clients, these mothers mentioned problems such as family tension, increased arguments among family members and the difficulties that the disturbed child created for siblings. Some also mentioned that the child had behavior problems. All of those interviewed reported that there was a crisis which had preceded the child's most recent psychiatric admission. This

crisis was generally manifested in acting out or passive behavior problems, but for some children (18%), the child's admission was the family's response to a crisis in which the child may have played a minor part, such as divorce, or the death of a relative.

When asked about problems in the nine specific service areas these parents of young children reported problems in the Social-Emotional area most often (43%). They described specific difficulties such as tension and stress or that the client gets other family members upset. Table 13 details the other specific problems mentioned by those interviewed.

Table 13 About Here

Housing, Food and Clothing and Education problems were mentioned frequently (24%, 21% and 19% respectively).

Families of these children asked for increased mental health services for themselves, such as family therapy/counseling, and more educational and mental health services to help them cope with their disturbed child. Like the families of the adult sample, these families reported that they rely heavily on psychiatric center staff and other mental health professionals to help them meet the clients' needs.

In summation, the children who were sampled from the records of five psychiatric centers in New York State appear to have spent a considerable amount of their childhood institutionalized because of mental health problems. Their families were often poor and sometimes had another family member who had a psychiatric problem. Family members were almost evenly divided in their perception of whether the child was a burden. The major problem areas identified by the family were Social-Emotional, Housing, Food and Clothing, and Education. Only half of the children receive

aftercare services though their previous psychiatric status indicates they are similar to the adult sample and the families have needs in the individual and family counseling service areas.

VI. SUMMARY AND CONCLUSIONS

A review of the major findings of this study reveals that severe stress is often experienced by families as a result of the homecoming of a mentally disabled relative. Although in some ways this sample is unrepresentative (few poor, very low or high functioning or non-white clients were included), the findings of this study have important implications.

Approximately one-half of the families interviewed reported that they felt burdened and families were frequently forced to make drastic life-style changes to accommodate the clients' return. These families asked for Social-Emotional services, such as family counseling and therapy, to help them deal with the stress of the client's return. Other important concerns to families and clients were Transportation, Employment and Homemaking problems.

The number of problems families expressed was related to the families' perception of stress as well as to certain client and family characteristics. It was found that families with chronically mentally ill clients, those who had clients who exhibited behavior problems, and those with clients who were low or moderately functioning, often reported two or more problems. The families of divorced clients and families who had a second mentally disabled member also reported more problems. These findings suggest that some high risk clients should not be discharged to their family's care.

The sample of families with mentally disabled children indicated that while many of these youth were severely impaired, only half received some form of aftercare services.

The following conclusions are based on the data from this study.

1. Families which reaccept mentally disabled members experienced great stress as a result of the client's return.

- Family members were providing primary care on a day-to-day basis for clients, many of whom would have remained hospitalized in the past.
- Data indicated that the return of the client to the family resulted in stress and tension within the family unit and necessitated major changes in the family's life-style.
- Families interviewed reported serious problems in caring for returned clients, including the inability to cope with the clients' constant need for supervision and altered and disturbed family interactions.
- Families living with mentally disabled relatives felt isolated and rejected by others in their community and perceived community members as not understanding mental illness.

2. Clients and their families were able to identify specific needs for services which, if addressed, would help alleviate their problems.

- The primary needs identified by both mentally disabled individuals and their families were in the Social-Emotional area. In particular, families and clients requested family counseling and therapy, additional outpatient services, and information and referral.
- After the Social-Emotional area, families identified Transportation and Homemaking problems most frequently. Requests were made for special transportation services and for reduced fares on public transportation. Homemaking needs included housekeeping services, financial counseling and respite care.
- From the client's perspective, job training and counseling, as well as sheltered and supported employment were crucial needs.

3. A major concern of families was the lack of activity and interaction displayed by the returned clients.

- Many clients were found to spend the day isolated at home with little to do. Many spent most of the day watching television or listening to the radio.
- Some clients specifically asked for day treatment programs in order to increase their outside-the-home activities.

4. It was apparent from the responses of the family members that they lacked information which would increase their ability to provide for their mentally disabled relatives.

- Although family members reported that they are asked to function as primary caretakers, they currently receive no training or education regarding the appropriate care of mentally disabled clients. Specifically, information was lacking about the clients' use of medication, community resources and services, and crisis intervention techniques.
- Data indicated that few of the families interviewed for this study participated in any informal support programs such as those organized by churches or other community groups.
- Most clients were receiving medication, many at levels similar to those received by inpatients and some cases of polypharmacy violations appeared to exist. Education regarding compliance, proper use and the side effects of medication is needed by families and clients.

5. Families were not involved in decisions regarding the provision of mental health services to their mentally disabled relatives. Family members did not participate in the planning and treatment process nor were they involved in discharge planning.

- Families were infrequently included in the discharge planning process. In fact, when asked why the client returned home, many families responded simply that the doctor said the client was ready to leave and that the decision was made without their participation.

6. Certain families appeared to be at high risk of experiencing problems in caring for returned clients.

- Data from the study suggest that families at high risk include those in which the client displayed serious behavior problems or was not functioning independently, or had been divorced, separated or widowed, and those in which a second family member had experienced mental illness.

7. Mentally disabled children and their families were found to experience problems similar in degree to those experienced by families with adult disabled members.

- Based on the subsample of mentally disabled children and their families, it was found that, except for age, these children were as likely as adults to meet all CSS eligibility criteria. Families of these children reported problems similar to those reported by families of adult clients but these children were less likely to receive aftercare services.

VII. RECOMMENDATIONS

On the basis of these findings, it is clear that the Office of Mental Health must pay greater attention to the needs of the families of mentally disabled individuals. This office should ensure that mentally disabled clients who are living with families, many of whom are eligible for Community Support programs, actually have the opportunity to participate in these programs. In the provision of community based services to mentally disabled clients, the active participation of other state agencies, such as the Departments of Social Services and Transportation, is also necessary. In order to support the Office of Mental Health in its efforts to establish policies and programs that will help families caring for mentally disabled individuals at home, the following recommendations are made:

RECOMMENDATION I: Services to be provided to mentally disabled individuals discharged to families should be specified in writing and agreed upon prior to the release of clients in a joint consultation between the psychiatric center staff, the family members and the client.

Services should include: day programming, especially job counseling and job training for the client; transportation of the client to mental health services; respite for the family; education for the family about client/family interactions and the use of psychotropic medications; provision of social-emotional supports; homemaking services; and rehospitalization of the client in times of crisis.

RECOMMENDATION II: It is recommended that family members be actively involved in discharge planning when their participation is appropriate and desired by the client.

Various alternatives of involving families in discharge planning should be considered by the Office of Mental Health. These could include: 1) developing new regulations regarding client's discharge to families that would specify aftercare services to be provided to clients and their families; 2) strengthening the existing Office of Mental Health regulation (Part 36.4(c) 4 and 5) which governs the community placement of discharged clients. Specific changes that could buttress existing regulations are: requiring a family member's signed consent to the client's discharge plan when that family member is the primary caretaker of the client; or providing families with the option of delaying reacceptance of the client if necessary aftercare arrangements have not been finalized.

RECOMMENDATION III: It is recommended that the Office of Mental Health establish as a priority the training of professional staff who work with mentally disabled clients residing in family settings.

Staff should be trained to view the family as a resource and a possible extension of the treatment team. Title XX training programs may be an appropriate mechanism to initiate training, but staff education programs of this type should eventually be available to all personnel involved in discharge planning and providing aftercare services to families of mentally disabled individuals.

RECOMMENDATION IV: It is recommended that a wide variety of family education programs be developed for family members who are living with mentally disabled relatives.

Pamphlets and other instructional materials should be developed and routinely distributed to clients and their families. Additional educational training sessions should include information about the proper use and side effects of medication, methods of dealing with clients' crises, and strategies for building family strengths.

RECOMMENDATION V: The Office of Mental Health's Committee on Therapeutics should thoroughly review medication policies and develop a policy or structure to monitor the medications of clients who live at home.

This review of medication policies should specifically include: an examination of polypharmacy violations, mechanisms for dispensing of medications to clients, and titration of medications to appropriate dosage levels. Serious consideration should be given to the development of a medication tracking system, similar to the tracking system currently used to follow inpatients' medications, to monitor medications used by outpatients.

RECOMMENDATION VI: Caseworkers and other direct service providers should be encouraged to maximize the use of informal supports in meeting the needs of mentally disabled individuals and their families.

Generic social service programs should be encouraged to include the mentally disabled and their families. Also, numerous informal support networks, such as the Mental Health Association's Compeer Program and the Community Friends Program have been developed in local communities. Service providers should be encouraged to utilize these programs, and other informal resources, which can be an effective complement to formal service programs. Active participation of local social service programs is critical and should be a major priority of the State Department of Social Services.

RECOMMENDATION VII: The Office of Mental Health should expand guidelines for local assistance programs to allow for the funding of informal support services for mentally disabled individuals and their families.

Several informal support groups already exist and additional community programs, which could be formed at minimal cost, should be initiated. In order to support the development of these programs, the Office of Mental Health should encourage counties to develop family support groups as part of their annual county plans and such programs should be eligible for local assistance funding.

RECOMMENDATION VIII: The Office of Mental Health should explore the most feasible and effective means of providing aftercare and supportive services for children and their families.

In the provision of mental health services to children, the respective roles of the Office of Mental Health staff, the Disabled Children's Program, the school system, local social service programs and local mental health clinics should be considered and clarified. Further, in view of the various agencies and programs that serve children, consideration should be given to expanding Community Support System eligibility criteria to include children.

RECOMMENDATION IX: Unless greater attention is given to the needs of families along the lines suggested above, it is recommended that the Office of Mental Health reconsider policy initiatives which assume that family members are appropriate substitutes for professional and para-professional mental health workers.

Both the strength of the family, as well as the health of the client must be considered at the time of the client's discharge from the psychiatric center. If the family does not have the necessary resources to support the client at home, and if the family is not provided with the necessary services to provide adequate care for the client, then alternative living arrangements should be made available.

REFERENCES

Derogatis, L. R., et al.
1974 "The Hopkins Symptom Checklist (HSCL): a self-report symptom inventory." Behavioral Science 19:1-15.

Doll, William, Edward H. Thompson, Jr. and Mark Lefton
1976 "Family coping with the mentally ill: an unanticipated problem of deinstitutionalization." Hospital and Community Psychiatry 27:183-185.

Dinitz, Simon, Shirley Angrist, Mark Lefton, Benjamin Pasamanick
1961 "The post hospital psychological functioning of former mental hospital patients." Mental Hygiene 45:579-588.

Freeman, Howard E. and Ozzie G. Simmons
1958 "Mental patients in the community: family settings and performance levels." American Sociological Review 23:147-154.

Lannon, Peter B.
1980 "NYS/NIMH community support project demonstration site evaluation: distinguishing characteristics of model community support systems." New York State Office of Mental Health.

Segal, Steven P.
1979 "Community care and deinstitutionalization: a review." Social Work (November):521-527

TABLES AND FIGURES

TABLE 1

Sex, Race, Age, Marital Status,
and Employment Status of Clients
(N=116)*

Characteristics	Clients %	Clients (N)
Sex:		
Male	49.1	(57)
Female	50.9	(59)
Race:		
White	88.8	(103)
Other	11.2	(13)
Age in Years:		
16 - 25	19.8	(23)
26 - 40	33.6	(39)
41 - 50	18.1	(21)
51 - 60	15.5	(18)
61 - 86	12.9	(15)
Marital Status:		
Married	27.5	(24)
Never Married	52.9	(46)
Widowed/Divorced/Separated	19.6	(17)
Employment Status:		
Employed	22.0	(24)
Unemployed	78.0	(85)

* Sample size may vary because information missing or unknown was omitted from calculations.

TABLE 2

Client's Psychiatric History and Status
(N=116)*

	%	(N)
Current Patient Status:		
Discharged	71.6	(83)
Never Hospitalized Outpatients	18.1	(21)
Awaiting Discharge	10.3	(12)
Age at First Admission:		
Less than 21	22.9	(19)
21 - 35	45.8	(38)
36 - 50	16.9	(14)
Over 50	14.4	(12)
Diagnosis:		
Schizophrenia	62.4	(53)
Affective Psychosis	9.4	(8)
Psychosis Associated with Organic Brain Syndrome	5.9	(5)
Neurosis	5.9	(5)
Other	16.4	(14)
Use of Medication:		
None	19.4	(19)
Single Drug Users	40.8	(40)
Multiple Drug Users	39.8	(39)
Dosage of Drugs:		
Light	21.1	(11)
Moderate	48.1	(25)
High	30.8	(16)

* Sample size may vary because information missing or unknown was omitted from calculations.

TABLE 2 - (continued)

	%	(N)
Receipt of Aftercare:		
Yes	81.8	(81)
No	18.2	(18)
Social Workers' Rating of Client Mental Illness Based on the Global Pathology Index:		
Absent	5.3	(5)
Minimal	16.0	(15)
Slight	14.9	(14)
Mild	16.0	(15)
Moderate	23.4	(22)
Substantial or More	24.4	(23)
Total Length of Hospitalization:		
One month or less	14.4	(13)
Greater than 1 one to 6 months	25.6	(23)
Greater than 6 months to 1 year	18.9	(17)
Greater than 1 year to 3 years	14.4	(13)
Greater than 3 years	26.7	(24)

TABLE 3

Clients' Ratings on
14 Functioning Items
(N=116)*

Functioning Items:	Independently		With difficulty or need of assistance		Not at all	
	%	(N)	%	(N)	%	(N)
Use public transportation on familiar routes	69.2	(63)	13.2	(12)	17.6	(16)
Use public transportation on unfamiliar routes	45.3	(39)	22.1	(19)	32.6	(28)
Drive a car	39.6	(40)	5.0	(5)	55.4	(56)
Manage his/her own money (e.g., has a checkbook, pays bills)	48.7	(54)	33.3	(37)	18.0	(20)
Manage his/her own program of medication	61.8	(63)	26.4	(27)	11.8	(12)
Perform household chores (e.g., cleans, makes beds, yard work)	68.7	(77)	17.0	(19)	14.3	(16)
Prepare or obtain his/her own meals	64.5	(71)	18.2	(20)	17.3	(19)
Engage in leisure time activities (e.g., hobbies like bowling, gardening, needlework)	55.3	(63)	17.5	(20)	27.2	(31)
Go shopping	65.2	(75)	19.1	(22)	15.7	(18)
Socialize with others (maintains contact with friends)	59.3	(67)	19.5	(22)	21.2	(24)
Write letters	59.1	(65)	11.8	(13)	29.1	(32)

Functioning Items:	Independently		With difficulty or need of assistance		Not at all	
	%	(N)	%	(N)	%	(N)
Use the telephone	87.8	(101)	7.8	(9)	4.3	(5)
Ask for help with problems (e.g., contacts physician, social security office, case worker or friend)	58.4	(66)	24.8	(28)	16.8	(19)
Care for the children	65.7	(23)	14.3	(5)	20.0	(7)

* Sample size may vary because information missing or unknown was omitted from calculations.

TABLE 4

Clients' Ratings on
14 Behavior Items
(N=116)*

Behavior Items:	None		Mild		Serious	
	%	(N)	%	(N)	%	(N)
Had trouble at work or school	49.3	(35)	18.3	(13)	32.4	(23)
Caused complaints from household members	56.7	(59)	28.9	(30)	14.4	(15)
Caused complaints from people in the community	87.9	(94)	8.4	(9)	3.7	(4)
Lost temper or self-control	47.3	(52)	30.0	(33)	22.7	(25)
Had trouble with the law	91.1	(102)	1.8	(2)	7.1	(8)
Destroyed property	86.6	(97)	9.8	(11)	3.6	(4)
Did nothing most days	46.3	(50)	25.0	(27)	28.7	(31)
Behaved in bizarre or unusual fashion	70.6	(77)	14.7	(16)	14.7	(16)
Disturbed other with unacceptable sexual behavior	90.0	(99)	6.4	(7)	3.6	(4)
Abused alcohol	86.5	(96)	6.3	(7)	7.2	(8)
Abused drugs	88.1	(96)	4.6	(5)	7.3	(8)
Stole property	92.8	(102)	3.6	(4)	3.6	(4)
Been dangerous to self	74.6	(82)	11.8	(13)	13.6	(15)
Been dangerous to others	85.6	(95)	9.0	(10)	5.4	(6)

* Sample size may vary because information missing or unknown was omitted from calculations.

TABLE 5

Clients' Level of Functioning, Behavior Problems, Activity and Interaction
(N=116)*

	%	(N)
Family Members Overall Rating of Clients' Level of Functioning:		
Low Functioning	28.7	(33)
Moderate Functioning	36.5	(42)
High Functioning	34.8	(40)
Family Members Overall Rating of Clients' Behavior Problems:		
Little or No Problems	38.4	(43)
Moderate or Serious Problems	61.6	(69)
Self Report of Clients' Level of Interaction with Others (outside the home):		
None	31.9	(37)
Family and/or Patients Only	5.2	(6)
Others	62.9	(73)
Self Report of Clients' Level of Interaction with Others (inside the home):		
None	13.8	(16)
Only with Immediate Family	71.5	(83)
With Others	14.7	(17)
Self Report of Clients' Level of Participation in Activities:		
Low	39.1	(45)
Moderate	34.8	(40)
High	26.1	(30)

*Sample size may vary because information missing or unknown was omitted from calculations.

TABLE 6

Selected Characteristics of Two Samples of Outpatients:
Study Sample and Community Support System Sample

	Study Sample (N=116)*		Community Support System Sample (N=624)*	
	%	(N)	%	(N)
Sex:				
Male	49.0	(57)	50.0	(312)
Female	51.0	(59)	50.0	(312)
Race:				
White	88.8	(103)	92.5	(570)
Other	11.2	(13)	7.5	(47)
Age at First Admission:				
Less than 21	22.9	(19)	20.6	(113)
21 or over	77.1	(64)	79.4	(427)
Diagnosis:				
Schizophrenia	62.4	(53)	59.0	(368)
Other	37.6	(32)	41.0	(256)
Receipt of Case Management:				
Yes	81.8	(81)	81.0	(505)
No	18.2	(18)	19.0	(119)
Mean Age:	40 years		50 years	
Marital Status:				
Married	27.5	(24)	12.3	(77)
Widowed/Divorced/Separated	19.6	(17)	34.1	(213)
Never Married	52.9	(46)	53.6	(334)
Use of Medications:				
Use	68.0	(61)	84.0	(524)
No use/missing	32.0	(37)	16.0	(100)
Level of Mental Illness:				
Absent	4.3	(5)	2.7	(17)
Minimal/Slight/Borderline	25.0	(29)	13.0	(81)
Mild	12.9	(15)	30.4	(190)
Moderate/Substantial	31.1	(36)	43.5	(271)
Marked/Severe/Extreme	7.7	(9)	8.2	(51)
Unknown	19.0	(22)	2.2	(14)
Length of Stay:				
Less than one year	58.9	(68)	35.4	(188)
One year or more	41.1	(48)	64.6	(344)
Mean length of stay	1.3 years		11.1 years	

* Sample size may vary because information missing or unknown was omitted from calculations.

TABLE 7

Characteristics of the Family Member
(N=116)*

	%	(N)
Sex:		
Male	31.9	(37)
Female	68.1	(79)
Race:		
White	88.8	(103)
Other	11.2	(13)
Age in Years:		
16 - 25	8.6	(10)
26 - 40	12.9	(15)
41 - 50	19.0	(22)
51 - 60	25.9	(30)
61 - 86	33.6	(39)
Respondent's Relationship to Client:		
Parent	46.6	(54)
Child	7.8	(9)
Spouse	27.6	(32)
Other	18.0	(21)
Employment Status:		
Employed	41.4	(48)
Unemployed	58.6	(68)
Income:		
Less than $5,000 to $10,000	47.5	(49)
$10,001 to $15,000	23.3	(24)
$15,001 to $20,000	11.7	(12)
$20,001 to $25,000	7.8	(8)
More than $25,000	9.7	(10)
Presence of Mental Illness in a Second Family Member		
Yes	31.5	(35)
No	68.5	(76)
Presence of Physical Disabilities in Family:		
Yes	36.3	(41)
No	63.7	(72)

TABLE 7 - (continued)

	%	(N)
Families' Perception of Clients' Mental Illness:		
Not at all	39.0	(39)
Mildly	30.0	(30)
Moderately	24.0	(24)
Very	5.0	(5)
Extremely	2.0	(2)

* Sample size may vary because information missing or unknown was omitted from calculations.

TABLE 8
Impact of Client's
Return as Reported by Families
(N=116)*

	%	(N)
"Is Living with a Mentally Disabled Relative a Burden?"		
Yes	48.7	(55)
No	51.3	(58)
"Did the Client's Return to the Family Result in Major Changes?"		
Yes	47.3	(43)
No	52.7	(48)
"Has the Client's Return Interfered with Leisure?"		
Yes	46.5	(53)
No	53.5	(61)

* Sample size may vary because information missing or unknown was omitted from calculations.

TABLE 9

Percent of Family Members, Clients and Interviewers Reporting Problems in Nine Major Service Areas*

Service Areas	Family Members	Clients	Interviewers
Social-Emotional	45.0 (Rank 1)	38.3 (Rank 1)	Rank 1
Employment	18.9	36.1 (Rank 2)	Rank 2
Transportation	21.4 (Rank 2)	27.2 (Rank 3)	Rank 3
Homemaking	19.6 (Rank 3)	14.9	
Food and Clothing	17.0	20.2	
Housing	18.6	15.0	
Legal	5.5	13.0	
Education	7.4	11.3	
Health	8.1	9.6	

* Because of multiple responses, percents sum to more than 100.

TABLE 10

Percent of Specific Subgroups of
Families Reporting Problems

TYPES OF PROBLEMS	TOTAL SAMPLE	PARENT CLIENTS	ELDERLY CLIENTS	LOW INCOME CLIENTS
Social-Emotional	45.0	85.1	77.8	50.0
Employment	18.9	42.9	55.6	33.3
Transportation	24.1	57.1	33.3	40.0
Homemaking	19.6	28.6	44.4	30.0
Food and Clothing	17.0	71.4	22.2	36.6
Housing	18.6	85.7	55.6	23.3
Legal	5.5	28.6	11.1	6.6
Education	7.4	0.0	11.1	20.0
Health	8.1	28.6	33.3	20.0

TABLE 11

Demographic and Social Characteristics of
Children and Family Members
(N=38)*

	Children		Family Members	
	%	(N)	%	(N)
Age:				
At least 9	10.6	(4)		
10 - 12	26.4	(10)		
13 - 15	36.8	(14)		
16 - 18	26.2	(10)		
22 - 30			11.1	(4)
31 - 40			50.0	(18)
41 - 50			30.6	(11)
Over 50			8.3	(3)
Race:				
White	61.1	(22)	59.5	(22)
Black	25.0	(9)	27.0	(5)
Hispanic	13.9	(5)	13.5	(5)
Sex:				
Male	71.1	(27)	21.1	(8)
Female	28.9	(11)	78.9	(30)
Position in the Family:				
Parent			89.5	(34)
Child	100.0	(38)		
Other			10.5	(4)

* Sample size may vary because information missing or unknown was omitted from calculations.

TABLE 12

Children's Psychiatric History and Status
(N=38) *

	%	(N)
Diagnosis:		
Schizophrenia/Psychosis	42.4	(11)
Personality Disorder	7.8	(2)
Acute Reaction to Stress	26.9	(7)
Other	22.9	(6)
Use of Medication:		
Yes	37.9	(11)
No	62.1	(18)
Length of most Recent Stay:		
One month or less	19.5	(6)
Greater than 1 month to 6 months	25.7	(8)
Greater than 6 months to 1 year	38.7	(12)
Greater than 1 year to 3 years	16.1	(5)
Length of Total Stay:		
One month or less	16.2	(5)
Greater than 1 month to 6 months	22.5	(7)
Greater than 6 months to 1 year	38.7	(12)
Greater than 1 year to 3 years	22.6	(7)
Receipt of Aftercare:		
Yes	53.3	(16)
No	46.7	(14)
Eligibility for CSS (excluding age criterion):		
Eligible	71.0	(22)
Ineligible	29.0	(9)

* Sample size may vary because information missing or unknown was omitted from calculations.

TABLE 13

Percent of Children's Family Members Reporting Problems in Nine Major Service Areas

	%
Social-Emotional	42.9
Housing	23.7
Food and Clothing	21.1
Education	18.9
Legal	16.7
Homemaking	15.8
Employment	15.8
Transportation	11.1
Health	2.1

Figure 1: Percent of Family Members and Clients Reporting Problems in Nine Major Service Areas

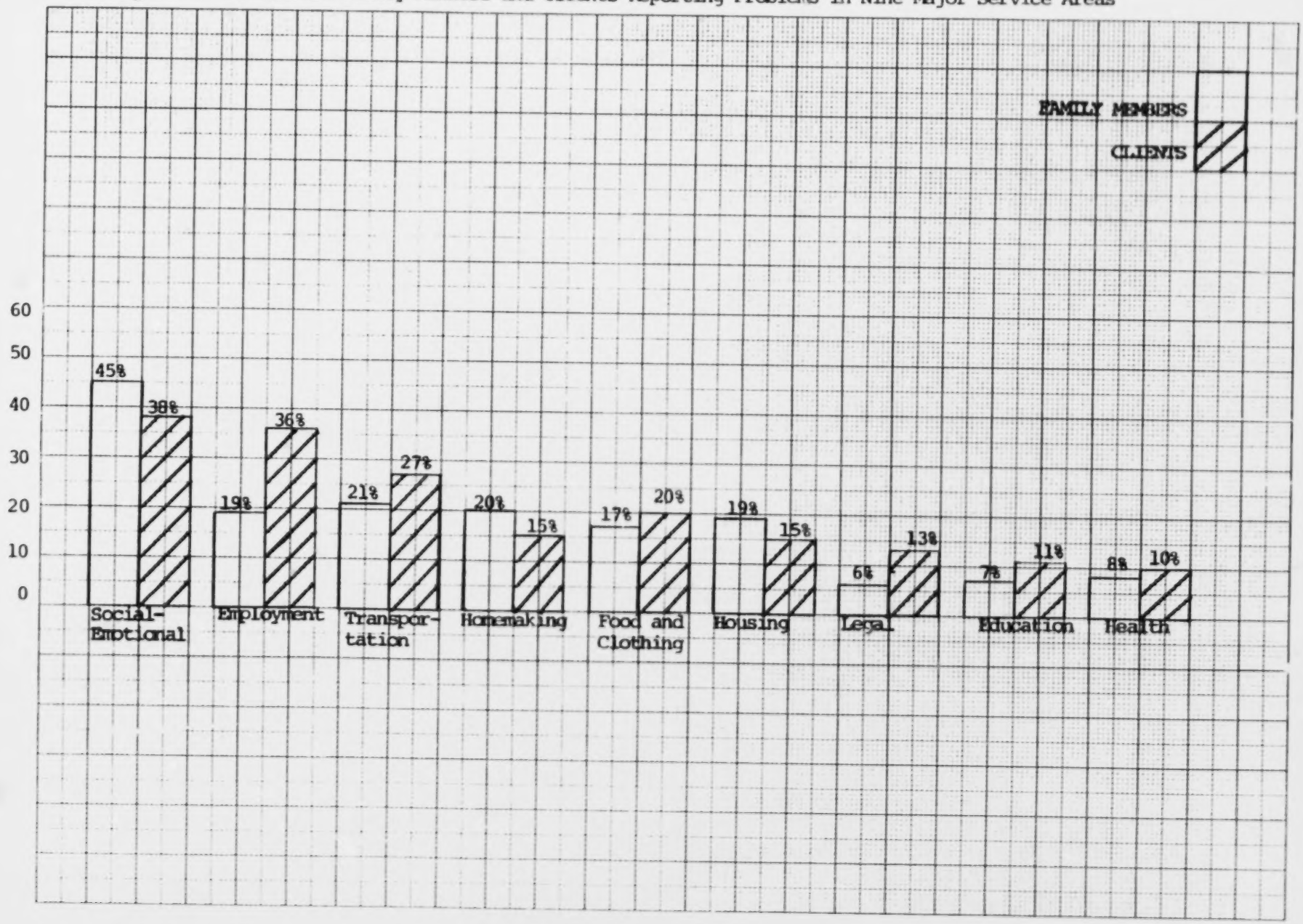

Figure 2: Percent of Problems Family Members Reported by Indicators of Family Stress

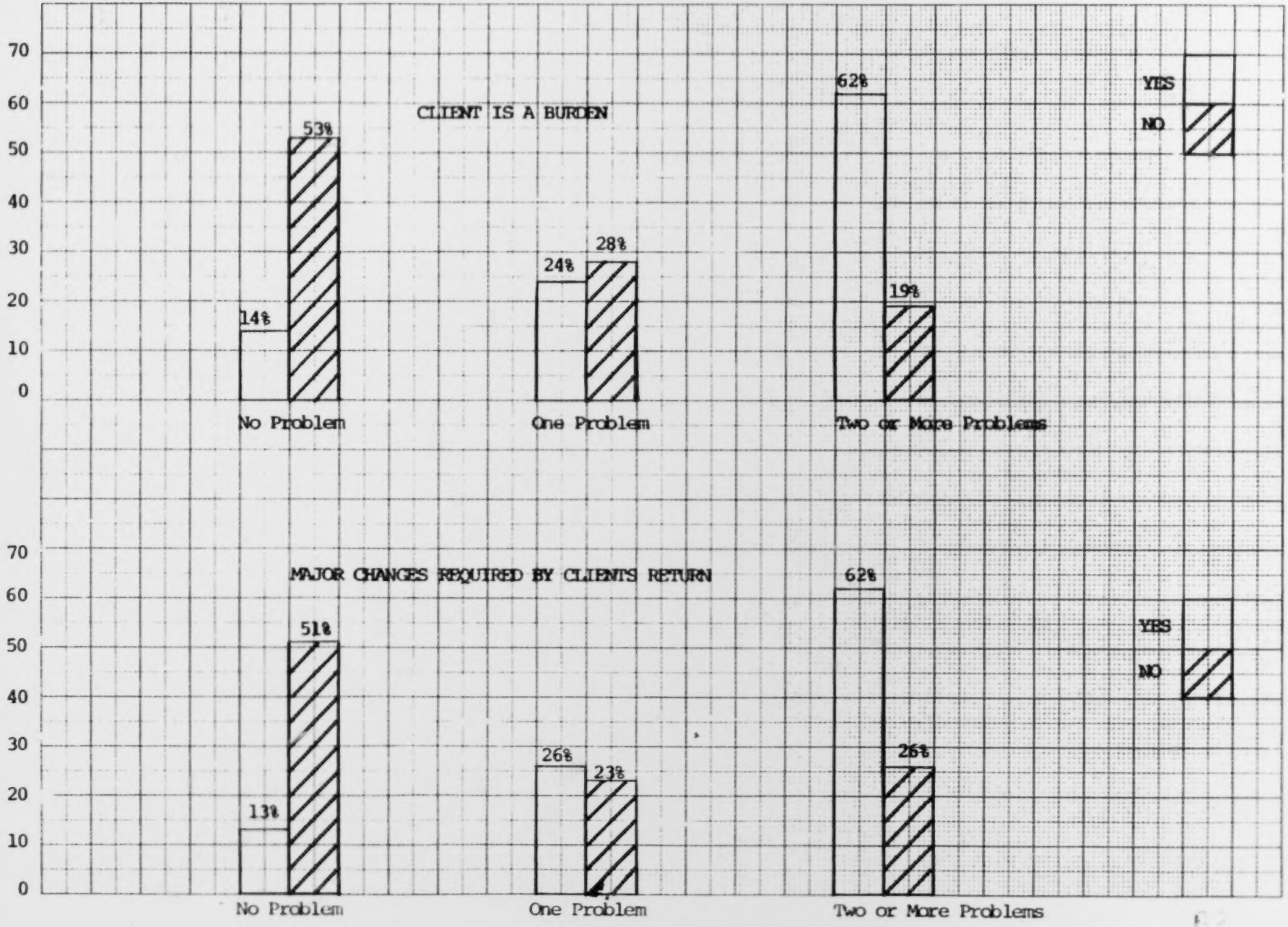

Figure 3: Percent of Problems Family Members Reported by Client's Chronicity

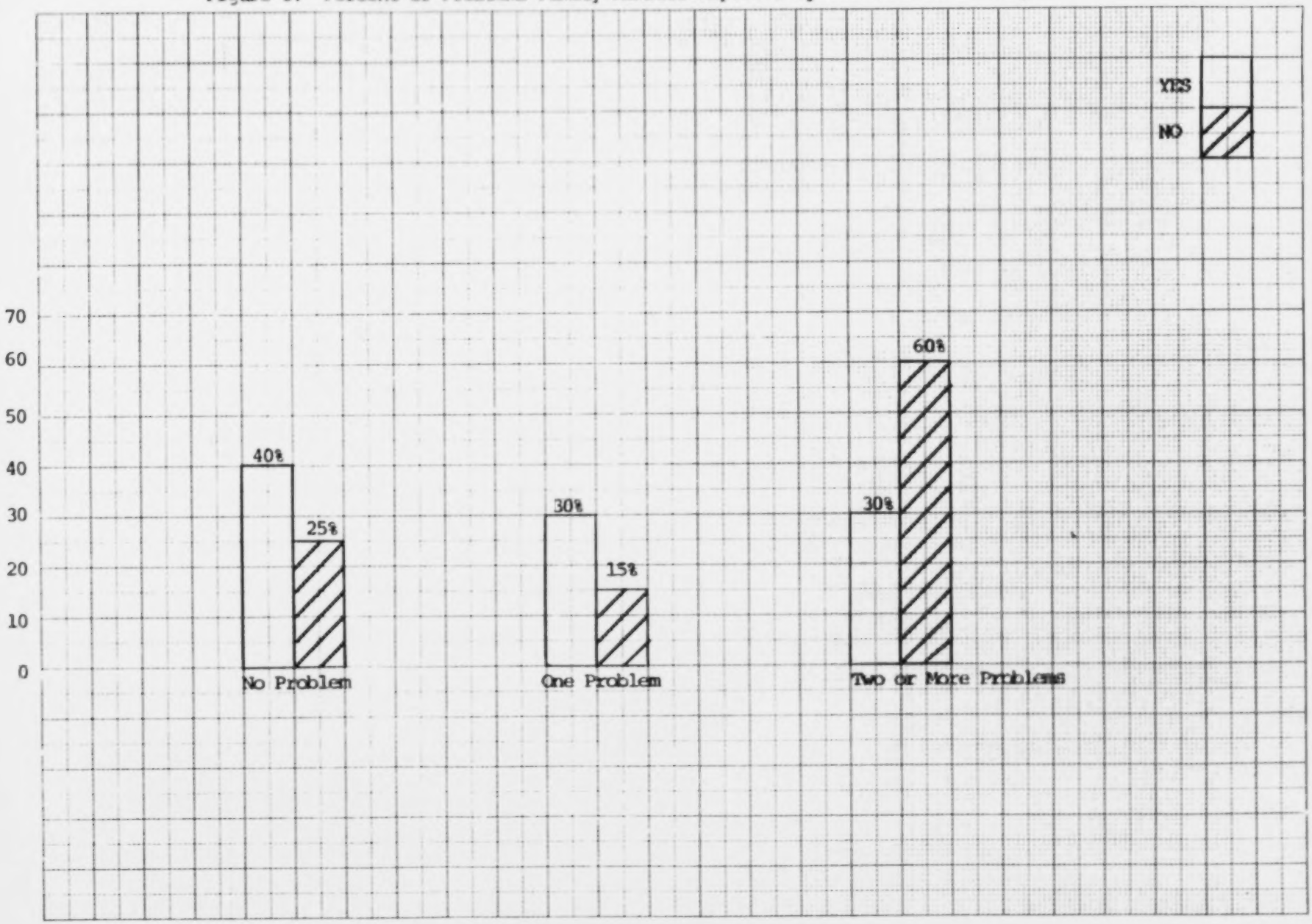

Figure 4: Percent of Problems Family Members Reported by Client's Behavior and Functioning

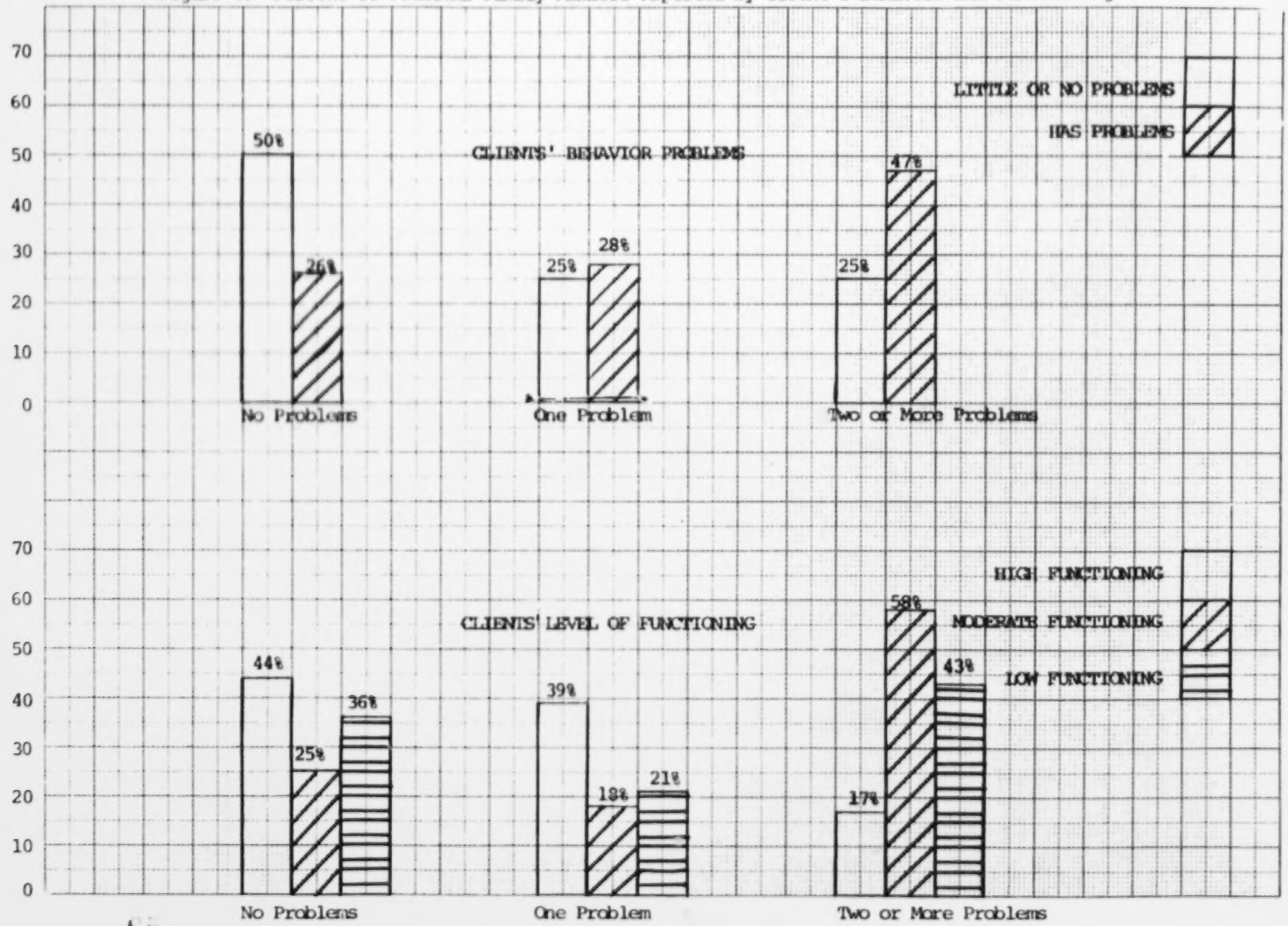

Figure 5: Percent of Problems Family Members Reported by Family Characteristics